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ABSTRACT

The paper reviews factors affecting the success of handicapped infant intervention programs. The absence of political leadership and support at the federal level, caused by changing political and economic conditions, is discussed. The practical programmatic issues affecting infant intervention which are considered include setting, staffing, handicap identification, and eligibility. A strategy for achieving universal intervention for handicapped and at risk infants is proposed which builds on existing political culture and law, especially Public Law 98-199, an amendment to the Education for All Handicapped Children Act which provides money to the states to develop and implement special education and related services to handicapped children from birth through 5 years of age. Additionally, Public Law 99-457, the Education of the Handicapped Act Amendments, 1986, uses a "bottom-up" approach by providing states with financial assistance to implement early intervention services to handicapped infants birth to 2 and their families. Provisions of this law are outlined in a summary which defines and explains "early intervention services," general eligibility criteria, the individualized family service plan, procedural safeguards, use of funds by the state as payor of last resort, and the role of the State Interagency Coordinating Council. (DB)

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Political, Economic and Practical Issues Affecting the Development of Universal Early Intervention for Handicapped Infants

by

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ABSTRACT

This paper reviews several factors that will affect the degree to which efforts to create an infant intervention program for all handicapped infants are successful. The absence of leadership from the Federal level, caused by changing political and economic conditions is discussed, along with several practical programmatic issues (setting, staffing, identifying). A strategy for achieving universal infant intervention, building on the existing political culture, is proposed. Finally, the provisions of P.L. 99-457, enacted in October, 1986, creating a discretionary infant intervention program, are outlined.

Helping to provide for the basic developmental and educational needs of children is an important function of government, and in this country all levels of government typically provide assistance in a variety of forms. This committment to providing services and programs to help optimize child development reflects not only a belief that government should help provide for the general welfare of all citizens but also the belief that early development is a critical time and that its course can be affected by environmental manipulation.

Both of these social policy concerns are frequently expressed in the legislative actions of government. In the Education of the Handicapped Act (EHA) concern for the general welfare is illustrated by the provision of financial assistance to States to require them to provide handicapped youngsters with an appropriate and free education. Preschool incentive grants and the direct support of early intervention research, demonstrations, and training reflect the second component, that early development is a critical time period.

Early intervention, however, has not enjoyed the same level of support as has special education programs operated in settings providing regular education to nonhandicapped children and youth in grades 1 through 12. Currently, special education programs for this population are universally available, and receive over one billion dollars annually in Federal financial assistance. In contrast, early intervention for preschoolers and infants who are handicapped is permissive, and the amount of Federal financial support is significantly less than that provided for the State grant program. In

addition, the level of services available varies from none in some states to a full range of services in others. And the availability of services varies by age: seven states provide services beginning at birth; one state at age 2; thirteen states and the District of Columbia at age 3; four states at age 4; and 15 states at age 5 (U.S. Department of Education, 1986). As is apparent, very few States offer such services to infants and toddlers; where early intervention is available, it is primarily available only to three- to five-year olds.

Two factors may help explain this age-related gap in provision of early intervention services to all handicapped youngsters: Federal leadership and the absence of clear data. With respect to Federal leadership, during the late 1960s and the 1970s, the Congress and frequently the Administration exerted a very strong presence in determining the degree to which special education would be made available to all youngsters who were deemed in need. In response to this leadership, the Federal government made available to States money to pay a portion of the excess costs over regular education costs that provision of such special services entails. In addition, the Federal government put in place civil rights protections and due process procedural mechanisms to help parents ensure that schools would be responsive to the special needs of their handicapped children. Today, many would argue that similar leadership in education and civil rights is not apparent, and that without a high degree of agreement between the Administration and the Congress, efforts to provide universal early intervention services will be seriously hampered.

With respect to data, there was no real need for supportive data to stimulate the provision of special education to handicapped children aged 6 through 18. Tax dollars paid for educational services, and to deny these benefits to one group of children while providing it to another was deemed discrimination and thus illegal. Persons promoting infant intervention however, have to make their case on the merits of the value of early intervention to the individual and the cost-benefit to society since discrimination is not an issue here (no similar universal intervention services are provided to nonhandicaped infants). Early intervention models and demonstrations have been in place for several years now, and many would argue that data now exists to show the promise of these efforts (e.g. Schweinhart, Berrueta-Clement, Barnett, Epstein, & Weikart, 1985; Garwood & Fewell, 1983; Greenspan & White, 1985; Ramey, Bryant, Sparling, & Wasik, 1985). Furthermore, as existing early intervention models and demonstrations have shown (e.g. Schweinhart,et al, 1985), the benefits of early intervention extend beyond the child. Parents, school personnel, instructional methodologies, community attitudes and expectations, and society in general are also likely to benefit. Consequently, universal early intervention with infants is increasingly seen as a desired social policy objective.

The major hurdle to be overcome if universal early intervention is to become available thus seems to be the absence of clear support by all components of the Federal government. This absence is evidence that there are problems that must be resolved before this nation is likely to be able to successfully implement universal early

intervention programs for infants with handicaps. Changing economic conditions and shifts in the dominant political ideology represent two areas of difficulty. In addition, there are serious practical questions that must be answered before programs of early intervention for at-risk and handicapped infants can become universal.

Political and Economic Constraints

From an economic perspective, the implementation of a social policy that is designed to maximize human development is expensive. As evidence, consider the many Federal programs to assist children and their families. These programs may be categorized as ones that (1) provide direct income assistance to children and their families; (2) fund in-kind assistance for children and their families; (3) support needed education and social services; (4) support research, technical assistance, training, and demonstration projects in areas related to child development; and (5) provide assistance to children and their families through tax deductions and credits. Collectively these five types of programs aiding children and their families number about 70 and in FY84 cost $134.3 billion to operate. The federal government continues to pay about 75% of these costs (Burke, 1985).

Currently, the Federal deficit is so great (approximately $212 billion) that the Congress has enacted legislation to automatically cut Federal social and defense spending annually by amounts needed to reduce the deficit to zero over a five year period. Only agreement by the President and the Congress on budget priorities can reduce sizable

automatic cuts in most Federal programs (P.L. 99-177, the Balanced Budget and Emergency Deficit Control Act of 1985) .

The effect psychologically and practically of this legislative deficit-reduction strategy is to shift the national debate from a discussion of how much money is needed to continue or expand programs to a discussion of such questions as " how much of a cut can programs take?" and "do we need to continue to operate expensive social programs?". Consequently, any serious move to significantly expand educational services or develop expensive new ones at the Federal level may meet with opposition, at least in the near future. Similarly, the reduction of Federal financial support for social services that will follow on the heels of severe deficit reduction efforts will likely mean a parallel increase in costs at the State and local levels, a factor that will likely weigh heavily in considerations for any expansion or development of new social services.

A second major issue to consider is the change in the U.S. political climate. The 1960s and 1970s were characterized by an expansion of Federal government services, reflecting a more liberal view of the role that government plays in our lives. The "War on Poverty" initiatives such as compensatory education and higher education programs, civil rights and voting rights legislation, and increased Federal aid to support access and equity for various groups all reflect this view. Higher taxes on the individual and on business, along with more government regulation of the actions of

individuals and business were necessary and parallel aspects of this trend. As a consequence, government grew larger and more costly and, in the view of many, became more intrusive in the lives of its citizens.

During the mid to late 1970s, more and more Americans began to express their dissatisfaction with the size of the Federal government and with some of its actions. Both Presidents Carter, a Democrat, and Reagan, a Republican, were elected after campaigning against the then current role of the Federal government, and since that time, the country has been undergoing a significant shift toward a more conservative view of the role of the Federal government. We have experienced deregulation, a reduction in federal taxes, and a move away from government's direct role in ensuring access and equity.

Accompanying this recent shift has been a change in the view of the role the Federal government plays in education. Those who hold a strict constructionist view of the Constitution believe strongly that education, because it is not mentioned in the Constitution, is a State and local responsibility. Currently, many political conservatives object to a strong Federal presence in education: only research and statistics is regarded as a valid Federal role. President Reagan's proposed education budget for FY87 attests to this view. Overall he proposes severe cuts in education programs but recommends an increase of about $10 million for educational research and statistics (Budget of the United States Government: FY 1987).

These two changes since the 1960s, our declining fiscal capability and the shift toward the right politically, thus have serious implications for any efforts to provide universal early intervention services for infants with handicaps. Without strong Federal leadership, it is likely that the development and implementation of a fully comprehensive early intervention program for at risk and handicapped infants must either await a shift in the dominant political ideology, back towards the left, as well as a significant upturn in the economy, or it must take place in a piecemeal manner over time.

Practical Considerations Affecting Infant Intervention

In addition to political and economic considerations, there are other issues of consequence that must be resolved before education for at-risk and handicapped infants and toddlers can become an effective reality.

One such issue is setting. Which public agency will play the lead role in providing early education intervention services? The State grant program created by P.L.94-142 provides Federal money to State and local education agencies to assist these educational agencies in providing special education services to handicapped children between the ages of 3 and 21 in educational settings.

Most State and local educational agencies were already providing some form of special education. Thus, schools found it relatively

easy to provide preschool classrooms in existing facilities. Those who elected to offer preschool special education found that three- and four-year-olds are not that much different from five- and six-year-olds. Instructional methods and materials could be modified without great difficulty. Accommodation to, and assimilation of, preschool handicapped children to the existing educational setting was therefore facilitated by these similarities.

However, such is not likely to be the case for infants. Their rate of development is more rapid; the kind, quality, and duration of services may be much more complex. New instructional methods, educational materials, and educational concepts will be needed. Additionally, at risk or handicapped infants and toddlers likely will require much more in the way of coordination of health and other social services across various agencies within a State, in addition to Education. Thus, while it is not clear that a "traditional" education seting is the best setting, there can be little doubt that the cost of providing early educational services to all at risk and handicapped infants will increase the State's costs significantly.

Another issue relates to the field's use of a definition to determine eligibility. Under a new initiative for infants, how would "handicap" be defined? Most diagnosticians will tell you that it is difficult enough, given the state of the art in human function testing to assess most behaviors with great accuracy. Age is a critical variable; the younger the child, the greater are the problems with reliable assessment. How then, given a very young population, can

infants be assessed reliably? As a consequence of this lack of measurement precision, there would likely be an increase in the number of young children determined eligible for service and thus an increase in the costs. Obviously, a new, cost-effective system for determining eligibility for this population would be needed. How it will be determined is important, not only for the viability of the program but also for its potential for labeling the infant in a harmful way.

Personnel staffing patterns and training is another issue. Many of the models of early intervention that have been developed rely quite heavily on a very small teacher-pupil ratio for intervention to be effective. Frequently such models are located near university and health care training facilities. Students enrolled in special education training programs at these institutions complete much of their practicum or internship requirements at these university-affiliated sites and thus provide, at very little cost, the needed personnel. Were these models to be translated into daily practice at infant education sites in every community, the number of trained educational personnel needed to staff infant and toddler intervention sites would likely be quite high, for inexpensive student trainee labor would not be nearly as available. Again, the costs of education would be made greater by this need for more intervention staff. In addition, we need answers about optimal staffing patterms, consequences of these patterns, and so forth.

Finding solutions to these practical considerations will not be easy. Leaving aside the fiscal and political issues raised earlier

for the moment, if Washington were to impose the answers on the States through the creation of a uniform program of universal early intervention, it could be an expensive "trial and error" proposition and it could could create resentment by taxpayers, practitioners, and parents alike. But if Washington does not exert some form of national leadership on this issue, the States may not take steps to develop universal early intervention for at risk and handicapped infants and toddlers.

Achieving Universal Early Intervention

Given the political and economic barriers mentioned earlier and the need to resolve some very basic practical considerations that drive up costs of universal early intervention, how do we achieve what the data indicate is good social policy? Elsewhere I have discussed the notion that policy activities exist and are shaped by a political culture. According to this view, effective changes in policy are those that represent a good fit between existing policy and proposals for new policy initiatives (Garwood, 1984).

Following this line of reasoning, successful achievement of universal early education for at risk and handicapped infants and toddlers could be enhanced by incremental extensions of current policy instead of a more drastic change. As an illustration, consider two different strategies.

One strategy would be to create a new infant component to the EHA.

Such an initiative, to be effective, would likely require a number of statutory changes and additions, including a new authorization and appropriation of money, creation of parallel administrative, programmatic, and due process procedures, establishment of eligibility criteria, and determination of inter-agency cooperative mechanisms. It would also require extensive negotiation with a variety of interest groups and others concerned with this legislation.

This strategy would represent a "top-down" approach, for answers to questions about eligibility criteria, personnel ratios, interagency cooperation, and so forth would likely be impcsed by Washington. Attempts to add such provisions from the top down would likely seriously disrupt the existing political culture of early intervention policy.

A different strategy would be to take advantage of existing law. Public Law 98-199, which amended part B of P.L. 94-142, directs the Secretary of Education to provide funds to help States plan, develop, and implement "...a comprehensive delivery system for the provision of special education and related services to handicapped children from birth through five years of age" (Sec. 623(b)(1) of P.L. 94-142, as amended by P.L. 98-199). Currently the size of the awards is relatively small, but by increasing the amount awarded to each State, more States could be encouraged to develop effective universal early intervention programs.

Attempts to implement universal early intervention using this

approach would likely be much less disruptive. While it too would require additional money, it is current law. Fewer statutory changes would be needed and thus fewer and more restricted negotiations would have to occur with interest groups, Members of Congress, the Administration, and others. This strategy would not present States or organizations representing various consumer or provider interests with the possibility of an increase or a decrease in regulatory activity.

This latter strategy would likely be less disruptive and would therefore represent a more acceptable alteration of the existing political culture. This second strategy would allow a bottoms-up approach to change, one that would allow States to discover, through their planning, development, and implementation process, how best to meet the early educational needs of at risk or handicapped infants.

Conclusion

There is little doubt that early intervention can be an effective procedure for increasing the ability of very young handicapped children to profit from their surroundings. There is also little doubt that educators and policy-makers agree that such early intervention efforts represent desirable social policy for national, state and local governments. The doubt comes when questions are raised about how to bring it about. Absent a strong Federal presence, success will likely be achieved only if efforts to institute a program of universal early intervention take into consideration the existing political culture and build incrementally new policy initiatives on

that context.

A New Beginning

In October, 1986, six months after the Gulf Coast Conference, the Congress passed and the President signed into law, a discretionary infant intervention program which is an amendment to the Education of the Handicapped Act (EHA). Public Law 99-457 uses a "bottems-up" approach by providing States with financial assistance to help them develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for handicapped infants and their families.

Handicapped infants are defined as individuals from birth to age two, inclusive, who need early intervention services because they (1) are experiencing developmental delays (as defined by a State, and as measured by appropriate diagnostic instruments and procedures or (2) have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay. The inclusion of the phrase "have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay" will enable States to serve infants who will need early intervention services even though many will not exhibit developmental delays at the time of diagnosis.

Definition of the term "early intervention services"

"Early intervention services" must satisfy seven criteria. First, they are provided under public supervision; the ultimate

responsibility for the provision of services remains with the lead agency designated or established by the Governor. Second, they must be provided at no cost except where Federal or State law provides for a system of payments by families, including a schedule of sliding fees.

Third, these services are designed to meet a handicapped infant's developmental needs in the following areas: physical development, cognitive development, language and speech development, psycho-social development, and self-help skills. Fourth, such services must meet the standards of the State. Fifth, early intervention services include, but are not limited to: family training, counseling, and home visits; special instruction; speech pathology and audiology; occupational therapy; physical therapy; psychological services; case management services; medical services only for diagnostic or evaluation purposes; early identification, screening, and assessment services; and health services necessary to enable the infant to benefit from the other early intervention.

Sixth, early intervention services are to be provided by qualified personnel, including, but not limited to, special educators, speech and language pathologists and audiologists, occupational therapist, physical therapist, psychologists, social workers, nurses, and nutritionalists.

Seventh, early intervention services are provided in conformity with an individualized family service plan, except that because infant development is relatively rapid and therefore undue delay could be

potentially harmful, such services may commence before the completion of the initial plan with the parent's consent.

General Eligibility Criteria

If a State elects to participate, during year one and two it may use funds received to plan and develop its early intervention system. In year three, the State must adopt a policy which incorporates all the components of a statewide early intervention system, and its statewide system must be in effect in year four. However, with respect to the development and implementation of the individualized family service plan, during year four, a State need only conduct multidisciplinary assessments, develop individualized family service plans, and make available case management services. Case management services assist families to gain access to early intervention services, assure timely delivery of these services, and coordinate their delivery with other needed services. Beginning in year five, all aspects of the statewide system must be available to all eligible infants in that State.

Individualized family service plan

Each handicapped infant and the infant's family must receive a multidisciplinary assessment of their unique needs and the identification of services appropriate to meet such needs and a written individualized family service plan developed by a multidisciplinary team, which includes the parents or guardian. This

plan must be evaluated at least once a year and the family must be provided a review of the plan at least at 6-month intervals (or more often where appropriate based on infant and family needs) to determine the degree to which progress toward achieving the outcomes are being made and whether modifications or revisions of the outcomes or services are necessary.

The individualized family service plan must be developed within a reasonable time after the assessment. However, with the parent's consent, early intervention services may commence prior to the completion of the assessment.

The individualized family service plan must be in writing and contain (1) a statement of the infant's present levels of physical development, cognitive development, language and speech development, psycho-social development, and self-help skills based on professionally acceptable objective criteria; (2) a statement of the family's strengths and needs relating to enhancing the development of the family's handicapped infant; (3) a statement of the major outcomes expected to be achieved for the infant and the family; the criteria, procedures, and timeliness used to determine the degree to which progress toward achieving the outcomes are being made; and whether modifications or revisions of the outcomms or services are necessary; (4) a statement of specific early intervention services necessary to meet the unique needs of the infant and the family, including the frequency and intensity and the method of delivering services; (5) projected dates for initiation of services and their anticipated

duration; (6) the name of the case manager from the profession most immediatly relevant to the infant's or family's needs who will be responsible for the implementaion of the plan and coordination with other agencies and persons; and (7) the steps to be taken supporting the transition of the handicapped infant to services provided under part B of the Act to the extent special education and related services are considered appropriate.

Procedureal safeguards

The procedural safeguards must provide, at a minimum, for: the timely resolution of administrative complaints by parents and the right to appeal to State or Federal court; the right to confidentiality of personally identifiable information; the opportunity to examine records; procedures to protect the rights of the handicapped infant whenever the parents or guardian of the child are not known, unavailable, or the child is a ward of the State, including the assignment of a surrogate; and written prior notice to the parents or guardian under specified circumstances; procedures to ensure that the notice is in the parents or guardian's native language, and procedures to ensure the provision of services pending the resolution of the complaint.

Payor of last resort

Funds provided under this law may not be used to satisfy a financial commitment or services which would have been paid for from

another public or private source but for the enactment of this part. However, the State may use these funds to pay the provider of such service pending reimbursement by the agency which has ultimate responsibility for the payment whenever considered necessary to prevent the delay in the receipt of the appropriate early intervention services by the handicapped infant. The State must develop a procedure for securing timely reimbursement as part of the statewide system.

Also the State is not allowed to reduce medical or other assistance available or to alter eligibility (to the detriment of handicapped infants) under title V (relating to maternal and child health) or title XIX of the Social Security Act (relating to Medicaid for handicapped infant) within the State.

State Interagency Coordinating Council

The law requires the establishment (which includes the designation) of a State Interagency Coordinating Council, and specifies its composition, rules governing its meetings, its management authority, its functions and responsibilities, rules governing conflict of interest and the use of existing councils. The Congress expects this will play a central role in accomplishing the State's early intervention effort. Thus, the Council is expected to provide meaningful advice and assistance to the lead agency in developing and implementing the policies that constitute the statewide system.

This new law presents all of us concerned with human growth and development with tremendous opportunities to help increase the richness of the lives of handicapped infants and their parents, to enhance our data base, to improve our service delivery models, and to refine and increase our theoretical speculations about the nature and direction of development.

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